

# MS-CCSVI-UK - VITAL Newsletter

[www.ms-ccsvi-uk.org](http://www.ms-ccsvi-uk.org) and [www.vital-now.org](http://www.vital-now.org)

Volume 2, Issue 2

July/August 2011

## Rally 2011

On the 4th May a small group of CCSVI supporters turned up outside Richmond House, the Dep. of Health Headquarters in Whitehall London. Initially we were a little disappointed that only 25 people attended, but then London is not an easy place to negotiate in a wheelchair. As it happens this small number turned out to be an advantage as we could not be said to be intimidating to any one on the inside. If a big crowd had turned out it is unlikely that we would have had a chance to talk to Andrew Lansley.

However he was not the only person we talked to. Quite a few people stopped to speak to us, were interested in what we had to say and wanted to know why we were there. A doctor/researcher working on the problems of diabetes talked to us for a good 10 minutes before moving on. He promised he would look at the information that we were handing out. By pure chance the niece of Ivo Petrov, a high profile surgeon from Bulgaria, just happened to be passing by and was surprised to come across us demonstrating about something so close to her



Talking to Andrew Lansley

family's heart. A freelance journalist spent some time taking details from us. It did not come to anything at the time but this contact may be useful in the future.

But the best bit of the day must have been when Andrew Lansley (The Health Minister) stopped to speak to the group on his return to his office from a meeting with the Prime Minister. Several people had a chance to explain what they wanted from the Department and the event was filmed for posterity. Mr Lansley appeared interested in our message but repeated the same thing the DoH has been saying for the past 18 months, namely: that 'the treatment had not been verified as safe for people with MS'. He also mentioned that NICE was going to be reviewing the case in the coming months.

**CCSVI News:**  
**Negative studies.**  
**VITAL News**  
**Partnerships**  
**MS Numbers**  
**Celebrities and**  
**Charitable status**  
**NICE report and**  
**developments**



Clear messages from Sandi and Pinda, two of the rally participants. More pictures inside.

## MS-CCSVI-UK



MS-CCSVI-UK logo

Our Facebook page set up in January 2010 is still going strong providing information and resources for the advancement of CCSVI treatment and research. Recently some new people have joined the admin team. Thanks and welcome to them.

Website:  
[www.ms-ccsvi-uk.org](http://www.ms-ccsvi-uk.org)

## VITAL



VITAL logo

Michele and Kevin created a facebook group called Vital-Now.org with a focus on ways in which we can make the treatment available for all on the NHS. It may also seek charitable status to raise funds for a legal challenge to the NHS. Vital also has a website:  
<http://www.vital-now.org>

## Pictures from the 4th May Rally

May the 5th is CCSVI day, it also happens to be around the time when we have elections in the UK and this year was no exception which is why we organized our rally for the 4th May. Here are a few of the pictures we took. Can you spot the VITAL logo?



Left: talking to passers-by in front of the Cenotaph  
Right: The crowd outside Richmond house.

Andrew Lansley listens to Kevin Campbell



The Houses of Parliament viewed through the railings



## Partnerships: Groups from around the world get together.

### CCSVI Ontario

Late in July we got an interesting proposal from CCSVI Ontario, suggesting that it would be a good idea to set up partnerships with like minded groups from around the world. In this way we can share information, successes and brick walls that we encounter. Although each country's situation will be slightly different because of the health care arrangements we all have commonalities which we can address in similar ways.

The health care situation in Canada is different to ours in the UK, even though they do have a national health service, they do not have the option of private medical insurance and a private health care sector. So in some respects Canadians are worse off than us as they have to travel abroad for CCSVI treatment whereas we can get treatment in our country.

Following from the idea of partnership Kevin thought that it would be a good idea to host these groups homepages on the VITAL website.

### CCSVI Australia

So far we have two partners who will soon be appearing on the [VITAL website](#). CCSVI Ontario and CCSVI Australia. The health care system in Australia is much the same as the NHS in the UK. They had an advantage over us in the UK in the recent past as the CEO of their MS Society was supportive of the CCSVI movement. Unfortunately this person is no longer in post and the situation is much more like our now. During this more benign atmosphere several people got CCSVI treatment from their local hospitals by appealing against refusal of investigation and treatment quoting the Equal Opportunities Act (equivalent to our Equality Act). Kerri Cassidy tells me that this strategy is unlikely to work in the present climate.

We are hoping that two more groups from the States will agree to us hosting their home pages. There is obviously a limit to how many pages we can host on our website. It is however an interesting concept.

### Collecting numbers

A couple of us have written letters to our doctors and PCTs to ask for the number of people diagnosed with MS in their practices. Early results indicate that the number of people suffering from this condition is severely underestimated. We need many more results to have a truer picture of the actual number and it would be great if a few of you could ask your own doctors or PCTs for their numbers. We have prepared a [letter](#) that you can send and there is also a list of [English PCTs](#) on the VITAL website.

I have written to the Department of Health asking for the same information but they

replied that there was no data collected for MS patients and referred me to this site: [NHS Choices](#).

I still have not heard from my PCT so not entirely sure if they collect this information. The MS Society is funding a research project aimed at collecting this evidence but it might be a couple of years before results are known. It would be a good PR tool for us if we could have some reliable figures before the MS Society do...

So if a few of our readers could write to their doctors for these figures (anonymous of course) it would enable us to get a better picture. Please let me have any data you collect: [michele.findlay@ms-ccsvi-uk.org](mailto:michele.findlay@ms-ccsvi-uk.org)

### Negative CCSVI studies and Zamboni's response to them

Recently neurologists have been falling over each other in the rush to publish negative results for their CCSVI studies in MS patients, and most often we do not have the benefit of an expert's evaluation of these studies. Recently though Prof Zamboni did make a comment on one of these studies and thankfully this puts the whole thing back on a level playing field, for me at least.

It stands to reason that if CCSVI had been easy to detect someone would have found out about it earlier. Veins are variable from person to person, much more so than arteries. I have heard also that not enough is known about the vascular system or the nature of blood pressure in the brain. It further stands to reason that if someone is trying to prove something wrong it is likely that their results will be negative.

The latest negative study was commented upon by Prof Alastair Compston, the MS Society UK neurological adviser, but as professor Zamboni remarked in his analysis of the study, opinion is not evidence. Professor Compston has history for spouting his opinion on CCSVI, most of us will remember his comment on the MS Society's website, first noticed in December 2009: "The treatment for CCSVI is not available for patients with multiple sclerosis in the United Kingdom because there is no convincing evidence to suggest that it is safe or beneficial to people with MS. People with MS are unlikely to benefit from treatments that dilate blood vessels."

Here is the latest negative study: <http://www.medscape.com/viewarticle/747957>

And here is Prof Zamboni's comment on the above: <http://www.facebook.com/notes/ccsvi-in-multiple-sclerosis/>

Also worth reading is Ashton Embry's [comment](#) on this topic.

Professor P Zamboni



### Celebrities, Companies, Charitable status

In order to proceed with a legal challenge to the NHS's refusal to treat people with CCSVI in spite of the treatment being freely available for other venous conditions, it will be necessary to form a company, and then seek charitable status. The reason this needs to be done is that without the status of charity we are unlikely to attract the funding we need. Although undoubtedly some of our members will be willing to contribute towards legal costs, it might be more realistic to get funding through charity events supported by celebrities and through corporate gifts who can claim tax benefits by donating to charities.

## NICE Meeting report

It was out of curiosity and interest in the process rather than any expectation of a recommendation of NHS treatment, that Kevin, Sarah, Cyndi and I went to this meeting which was to evaluate the validity of CCSVI treatment in people with MS. As you will know from our previous communications we believe that Venous Insufficiency should be treated whether someone has MS or not. It is a common place and safe procedure which is carried out daily in our local hospitals.

It quickly became clear that CCSVI was a new concept for the physicians who presented the CCSVI treatment case and although they had done some homework it was apparent that they were not familiar with the issues and were having trouble drawing any conclusions about treatment. John Rose (IR) admitted that routine venoplasty itself was commonplace and that the risk attached to it were acceptable at 1% or 2%. Regarding CCSVI intervention Monica Leighton (GP) remarked on the two negative events that happened early on in the history of the treatment carried out by Dr Dake at Stanford USA, but no mention was made of this as a percentage of procedures carried out to put these negative events into perspective revealing that venoplasty carried out on MS patients has been shown to be 100 times safer than the acceptable risk Dr Rose mentions above.

### NICE explained and the process for issuing 'guidance'.



Midcity Place, London where NICE have their headquarters.

For those of you not familiar with NICE, it stands for National Institute for Health and Clinical Excellence and is a semi independent body that examines the validity of drugs and procedures to see whether they are safe and effective for the NHS to use. Their [website](#) says this about how they work:

“NICE works with experts from the NHS, local authorities and others in the public, private, voluntary and community sectors - as well as patients and carers. We make independent decisions in an open, transparent way, based on the best available evidence and including input from experts and interested parties.”

There are opportunities for people to contribute to their process of issuing guidance. In fact this application was made by an MS patient. The problem that we may have with this is that there was no one at the meeting who knew very much about CCSVI and its treatment. Whereas if the application had been presented by a knowledgeable physician the case may have been better put. This process however takes about 6 months and in that time there will be several meetings and opportunities for patients and other people with an interest in the subject to make contributions. The consultation period for our application starts on the 24th August. Contact: [emma.chambers@nice.org.uk](mailto:emma.chambers@nice.org.uk)

Professor Campbell remarked that very little response to the survey had been received from patients who had undergone the intervention in this country. In fact he had only received two replies that very morning and we felt rather disappointed about that as it appeared as if there was not much enthusiasm for this treatment (we later found out that the survey had not been received in time for responses to be heard at the meeting). We thought that the committee was rather short on evidence and it was a shame that the surgeon carrying out the interventions in Scotland was not present.

In earlier discussions on another topic the committee was quite ready to accept the possibility of an intervention that had limited benefits for a patient, however in our case no view was expressed on this aspect of CCSVI treatment. This appeared to be due to the opinion of the people presenting the case that there was not enough evidence to suggest that this had any benefits at all for patients, there was even a question posed (by Dr Leighton) as to whether this procedure might be more dangerous for people with MS.

The person representing patients with disabilities, Ms Sue Bennett, a wheelchair user herself, said that she was concerned that no harm should be caused to MS patients by this procedure.

Full report available here: [www.vital-now.org](http://www.vital-now.org)